Effect of participation in a randomised controlled trial of an integrated palliative care intervention on HIV-associated stigma

Short title/running head: Resistance to HIV-associated stigma

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Abstract

We conducted in Kenya a mixed-methods randomised controlled trial (RCT) of a nurse-led palliative care intervention integrated with anti-retroviral therapy (ART) provision for the management of HIV. Here we report qualitative findings showing increased resistance to HIV-associated stigma among trial participants. A mixed method design was chosen to enable identification of the active ingredients of the intervention and exploration of participants' experiences of receiving the intervention. The RCT was conducted from July 2011 to November 2012 in a community hospital in the city of Mombasa, Kenya, with a sample of 120 adults with HIV on ART. Thirty participants were purposively selected to take part in a qualitative exit interview, based on study arm and mental health outcome.

Inductive thematic analysis revealed increased resistance to HIV-associated stigma in both the intervention and control groups. Specifically, patients in both groups described benefit from the social support, compassionate care, and open and respectful communication they received through study participation. Participants described improved self-image, increased access to social agency, and increased resistance to HIV-associated stigma. Our findings suggest that there is potential to increase resistance to stigma through simple mechanisms of support, compassion, and improved communication in routine care. The self-reported impact of trial participation on stigma also has implications for future trials in populations in resource-constrained settings where stigma is common.

Keywords: HIV/AIDS; Stigma; Shame; Palliative Care; Kenya;

Introduction

Stigma was defined by Goffman in 1963 as a mark of social disgrace, where the stigmatised are excluded from social acceptance and are socially devalued (Goffman, 1963). Although commonly understood at the individual level (Herek, Saha, & Burack, 2013a), or the macro-societal level (Parker & Aggleton, 2003), an appreciation of both acknowledges how social processes become part of a stigmatised other's identity making resistance at an individual level very difficult (Catherine Campbell & Deacon, 2006). The persistence of HIV associated stigma, is a threat to progress in the control of HIV internationally (Stangl & Grossman, 2013), a barrier to testing (Dapaah & Senah, 2016), prevention of mother-to-child transmission (Turan & Nyblade, 2013), and, once diagnosis is confirmed, stigma remains a barrier to PLWH accessing adequate healthcare (Bogart et al., 2013; Dasgupta, Sullivan, Dasgupta, Saha, & Salazar, 2013). It is also associated with non-adherence to antiretroviral therapy (ART), increasing the risk of viral resistance (Mhode & Nyamhanga, 2016; Sweeney & Vanable, 2016).

Community members often distance themselves from PLWH due to stigma (C. Campbell, Foulis, Maimane, & Sibiya, 2005; Visser & Sipsma, 2013), denying their own risk of contracting HIV, putting themselves at increased risk of transmission and delayed diagnosis (Nyblade et al., 2003). Among PLWH, the social ramifications of disclosure increase the risk of transmission through reluctance to openly take medications or negotiate condom use with a sexual partner (Mbonu, van den Borne, & De Vries, 2009; Turan & Nyblade, 2013).

In addition to these public health concerns, there is evidence that people experiencing HIV-associated stigma report less healthcare utilization, and poorer

physical health (Bennett, Traub, Mace, Juarascio, & O'Hayer, 2016; Herek, Saha, & Burack, 2013b). HIV-associated stigma also manifests as social isolation and rejection (C. Campbell et al., 2005; Owolabi et al., 2012), increasing depression (Palmer et al., 2011; Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012), anxiety (Adewuya et al., 2009) and low self-esteem (Visser & Sipsma, 2013). A recent study suggests that this relationship between HIV-associated stigma and psychological well-being may be mutually reinforcing (Miller et al., 2016).

The international community struggles to identify stigma reduction interventions that are effective for HIV-related health outcomes (Stangl, Lloyd, M Brady, Holland, & Baral, 2013). Studies are often methodologically weak due to predominant use of locally-created and/or un-validated outcome measures, which inhibit interpretation and comparison across studies (Sengupta, Banks, Jonas, Miles, & Smith, 2011; Stangl et al., 2013).

HIV-associated stigma also presents high costs for society (direct and indirect effects of stigma reduction have been valued at a potential $1000 per point on the Berger Stigma scale) (Brent, 2016).

We conducted a randomised controlled trial (RCT) of a nurse-led palliative care intervention for PLWH established on ART in Mombasa, Kenya (Lowther et al., 2012, 2014, 2015). In qualitative exit interviews, the themes of stigma, resistance to stigma, and the effects of participation in the research, emerged inductively as highly salient to participants. In this paper, we aim to describe experiences of stigma and stigma resistance among PLWH enrolled in the trial, and to draw out implications for clinical practice and research.

Materials and methods

The Treatment Outcomes in Palliative Care (TOPCare) study was an RCT of a nurse-led, integrated palliative care intervention for HIV positive patients conducted in a clinic in Mombasa, Kenya. The trial had an embedded qualitative component with a sequential, explanatory design (Ivankova, Creswell, & Stick, 2006). Study methodology is reported elsewhere (Lowther et al., 2012), as are details of recruitment, follow up and missing data (Lowther et al., 2014), and results of the trial (Lowther et al., 2015). We found the intervention had significant positive effect in terms of mental health and well-being, but no effect on pain or physical outcomes (Lowther et al., 2015).

The intervention consisted of 4 months of palliative care integrated into patients' routine HIV outpatient care. It was delivered by two experienced HIV clinic nurses who received two weeks' specialist training in palliative care from the Kenyan Hospice and Palliative Care Association and clinical support and mentoring from local hospice nurses. The training covered pain management, symptom management, nutrition, psychosocial and spiritual assessment and care, breaking bad news, ethical and legal issues, and bereavement. Participants in the intervention arm received a minimum of 7 appointments (approximately 45 minutes long) with one of the two intervention nurses. The nurse delivered person-centred care which included a holistic assessment of emotional, spiritual, social and physical well-being, patients' understanding of HIV, and ability to maintain treatment adherence. This assessment informed care delivery, with hospice referral for complex cases of pain and symptom management. Control arm participants received standard care in the Comprehensive Care Clinic (CCC) at the study site, which consisted of monthly

appointments usually lasting 5-7 minutes. They were seen by HIV clinic nurses with similar levels of experience but without the additional training.

Sampling

Participants who met the inclusion criteria for the wider trial were aged ≥18, HIV positive and on ART for more than one month, and reported moderate to severe pain or symptoms lasting at least 2 weeks, as measured by the African Palliative Care Association Palliative Outcome Scale (APCA POS (Harding et al., 2010)). The sub-sample recruited to the qualitative component of the study was purposively selected based on study arm allocation and individual quantitative response to participation in the trial. Participants from the intervention arm were over-sampled (10 control /20 intervention) to enable in depth exploration of the active ingredients and mechanism of action of the intervention (data to be reported elsewhere). Sampling was in line with a sequential explanatory mixed methods design: we purposively selected participants to achieve a maximum variation sample based on individuals' clinical response to the intervention. Response was measured using the Medical Outcomes Survey – HIV Mental Health Summary Score (MOS-HIV MHSS), the mental health subscale of a well-validated, disease-specific quality of life measure (Wu, 1999). A change of 10 points on the MOS-HIV MHSS is considered clinically significant (Wu, 1999). Participants were categorised as "improving" if they improved by ≥10 points during the four-month study period, "static" if there was <10 points change in either direction, and "deteriorating" if they decreased by >10 points over the study period.

A sample size of thirty qualitative interviews was chosen to balance opportunity for data saturation with feasibility of in-depth analysis (Sandelowski, 1995).

Data collection

Data collection in both groups involved five quantitative data collection appointments at monthly intervals, with selected participants invited to take part in a qualitative interview from 1-8 months post trial exit.

The same Kenyan researcher (NG) who collected the quantitative data throughout the RCT conducted the qualitative exit interviews. The researcher was skilled and experienced in qualitative research, provided with study-specific training, and bilingual in English and Swahili. The interviews lasted approximately 45 minutes, and were guided by a semi-structured topic guide developed by the study group. The topic guide included questions about participants' physical, psychological, social and spiritual well-being before, during and after the study, in line with the holistic nature of the palliative care approach (WHO, 2013). Participants were also asked about their experiences of participating in the study, and, if allocated to the intervention arm, their perceptions of the differences between the two models of care (intervention vs standard care).

The interviews were conducted in a private location at the study site in either English, Swahili or both, depending on participant preference. Participants were welcomed into the study setting, and given refreshments to demonstrate hospitality and respect. The interviews were digitally recorded, transcribed and translated into English (where needed) by an experienced translator. Translations were quality checked by the researcher against the interview recordings, and amended if inaccuracies or errors were identified.

Analysis

Transcripts were analysed thematically using a combination of deductive and inductive coding (Braun & Clarke, 2006). Deductive themes were identified according to the domains of well-being integral to palliative care (physical, psychological, social and spiritual), while additional themes emerged inductively. Themes were defined as codes or collections of codes containing elements which represented a patterned response or concept (Barbour, 2013). Following Barbour, the following questions were posed to identify themes, with constant reference to the study objectives: "Which codes are repeated? How do they relate to each other? Do these codes relate as sub-themes or associates in that they occur simultaneously?" (Barbour, 2013). Once identified, themes were organised hierarchically into major themes and sub-themes, according to their meaning and relationship to each other, to structure and reduce the volume of data. Major themes were those with high levels of salience and significance, in terms of understanding the therapeutic aspects of the intervention and their repetition across the dataset. Analysis was managed using NVivo 9 software. Findings are presented using anonymised illustrative quotes, annotated with the participant's gender, age and intervention arm (Tables 2 and 3, cross-referenced in the text).

Ethics

Ethical approval was provided by King's College London Research Ethics Committee (BDM/10/11-31) and the Kenyan Medical Research Institute (KEMRI/RES/7/3/1). All patients gave written informed consent (if the participant was unable to read or write, the information sheet was read aloud and a thumb print given to indicate consent).

Results

Sample characteristics

30 participants were interviewed; no one approached declined. Participants were similar to the wider trial sample in terms of clinical and demographic characteristics (Table 1). Mean age was 39.1, with a mean of 2.4 children and 3.2 financial dependants. Most were women (80%, n=24), and two-thirds (67.7%, n=20) completed primary school as their highest educational attainment. Interviews were conducted from one to eight months after trial exit (mean 4.2 months). The research team judged that data saturation was reached in that no new themes emerged from the analysis of later interviews.

[INSERT TABLE 1 NEAR HERE]

Findings

Stigma arose inductively in the data as an important characteristic of participants' experience of living with HIV, described by 25 of the 30 participants. Findings regarding stigma are presented in two themes: experience of HIV-associated stigma, and effects on HIV-associated stigma of participation in the trial.

Experience of HIV-associated stigma (Table 2)

When asked to describe their well-being before study participation, many participants described the experience of stigma indirectly, in terms of a fear of disclosure of their HIV diagnosis. They anticipated that this would lead to being shamed, socially isolated or discriminated against (quote 1). Participants reported hiding their status behind diagnoses which were more socially acceptable to their networks, for example saying they had tuberculosis (TB). The HIV positive diagnosis led some

participants to self-hatred and suicidal ideation. One participant described how internalised stigma, from cultural norms associating HIV with immorality, created an identity crisis (quote 2). Once they disclosed their HIV status to others, some participants reported experiencing anger and blame from their families and other community members (quote 3).

Experiencing this enacted stigma or discrimination against PLWH, either directly or vicariously, discouraged participants from disclosing their status, which led to increased isolation and suffering. Social isolation was a major cause of sadness; friends from before they were diagnosed had left, increasing their sense of vulnerability and isolation (quote 4)

[INSERT TABLE 2 NEAR HERE]

Effects of participation in research on HIV-associated stigma (Table 3)

During the counselling received in clinical appointments, intervention participants were encouraged by the study nurses to see themselves as normal, just like any other person. This was reported to improve self-esteem, self-image and acceptance, and help participants resist internalised stigma (quotes 5-7). Some intervention arm participants described dramatic changes in their outlook, from suicidal to positive (quote 8). However, the beneficial effects of participation also extended to those PLWH in the control arm, with both groups of participants describing the therapeutic effects of their interactions with the study team (quotes 9, 10)

Participants built a trusting relationship with the researcher who administered the study questionnaires, owing to the compassion they witnessed, and her non-judgemental and open communication style. They described how this way they were treated, enabled them to rebuild a positive self-image (quotes 11, 12). This change in

self-regard was often described as a shift in seeing themselves as normal rather than abnormal, and worthy of respect, social interest and engagement (quotes 13, 14). Participants described how, through this growth in self-esteem, they were more able to reject stigmatising messages, and became confident in disclosing their HIV positive status to their close communities (quote 15). Being treated as a normal person by a health care practitioner was in stark contrast to the advice received by one participant attending the standard clinic, who reported she was advised to 'behave normally' when she received her diagnosis, in case people realised that she was HIV positive (quote 16).

One of the most powerful aspects of participation in reducing internalised stigma was being given the space and permission to talk (quotes 17, 18). Some participants clearly attributed the effect to the process of completing the outcome measurements (quotes 19, 20). Because of participation in the study and the support they received through attending data collection appointments, some participants made concrete changes to their social situations (quote 21). Others became activists in less public ways, making themselves available to others for counselling and support, particularly those who had recently received their diagnosis. They described having the confidence and self-belief to act normally, interacting with their communities accordingly, and ignoring the stigmatising responses they had previously anticipated and feared. These newly created identities as 'activists' were socially acceptable and added purpose to participants' lives participants (quotes 22, 23).

[INSERT TABLE 3 NEAR HERE]

Discussion

The findings of this study demonstrate the therapeutic value of a relationship characterised by compassionate care, social support, and open and non-judgemental communication. While intervention group participants described benefit from their appointments with the study nurse, participants in both groups described the way that simply participating in the trial's data collection procedures helped them to increase their resistance to the stigma associated with HIV.

The researcher completed standardised patient reported outcome measures with each participant at regular intervals over a four-month time-period. She had no therapeutic remit or training, yet participants clearly described therapeutic benefit, including increasing ability to resist stigma. We can see two possible reasons for this. Firstly, the act of being asked questions about their well-being and problems may have served to acknowledge their importance. Secondly, being accepted and treated with respect may have helped patients renegotiate a positive self-identity.

This second hypothesis is supported by other studies of HIV-associated stigma (Goudge, Ngoma, Manderson, & Schneider, 2009; Soskolne, 2003). In a study in South Africa, women living with HIV described how, given time, they were able to negotiate a new positive self-identity which helped them cope with anxiety and the stigma of their HIV diagnosis (Soskolne, 2003). The work of Goudge et al. (2009) describes the crucial role of social support – the very thing lacking when stigma is present and powerful - in this process (Goudge et al., 2009). They found that through social support, PLWH were able to express their emotions, make sense of their diagnosis and move towards a problem-solving approach toward managing their health,

whereas those with less support were less able to adjust and cope (Goudge et al., 2009).

The shift observed in our participant group can also be understood through the lens of shame and shame resistance theories. Van Vliet's theory of shame resistance states that to improve the affected person's self-concept individuals must undergo a process of reconstruction, rebuilding a new identity in response to a shaming experience (Van Vliet, 2008). She describes the five sub-processes this involves: connecting, refocusing, accepting, understanding and resisting (Van Vliet, 2008). These sub-processes appear to mirror our participants' descriptions of their experience of participating in the trial. Connecting and refocusing are described when patients talk of the social support they received from the research team. Acceptance can be seen in their descriptions of learning to accommodate their HIV status, in part through the acceptance they experienced from the research team. Participants receiving the intervention described being treated as normal people, told that they were normal and advised that should treat themselves accordingly, as particularly potent aspects of the intervention. Central to acceptance was coming to understand that anyone, even morally 'good' people, can get HIV. The final sub-process in Van Vliet's theory is resistance. Using their reformed identity and renewed positive self-image as 'good' or 'normal' people, some participants expressed stigma resistance through becoming an activist or supporter of other PLWH. Others expressed their resistance through reaching out to rejecting family members, deciding not to be ashamed, and widely disclosing their HIV status.

Our findings regarding reforming identity reflect those of Aujoulat et al.'s study (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008), in which chronically ill

patients described a process through which they managed to resolve their identities as 'people living with a disease', not as 'diseased people'. Aujoulat et al. describe the processes through which individuals come to terms with a disrupted 'well' or 'normal' identity, manage the threat to their security and identity which illness represents, and face the lack of coherence or meaning which often accompanies diagnosis (Aujoulat et al., 2008). This reflects our own data and the wider HIV literature, which highlights that resistance for PLWH involves re-negotiating control over health and illness (Brinsdon, Abel, & Desrosiers, 2017; Goudge et al., 2009).

Our findings suggest that healthcare systems can play a role both in perpetuating and alleviating HIV-associated stigma. Research from South Africa also describes how women attending health care settings appreciated positive interactions with staff, while negative experiences further stigmatised (Okoror, BeLue, Zungu, Adam, & Airhihenbuwa, 2014). Recent research from Bangladesh demonstrates how a sexual and reproductive health rights training package administered to health care workers can reduce the stigma experienced by their patients. This study found that indicators of HIV-associated stigma among healthcare workers were reduced, alongside an increase in patient satisfaction with services (Geibel et al., 2017). In our study, the participants witnessed a working example of supportive, stigma-free care, and help to manage stigma through the provision of space to disclose and discuss openly.

An alternative explanation for the shift we observed in how participants felt could be that participants adjusted to their diagnosis over time. However, this sample of participants had been diagnosed with HIV for a median of 3.5 years (IQR 1.3-5.2) and had been on ART for a median of 2.5 years (IQR 0.8-4.2), therefore it is unlikely that this is the sole explanation. It might also be that the intervention itself, rather

than trial participation, improved stigma resistance. However, the striking similarity between the changes described by both control and intervention arm participants suggests otherwise. There was no contamination in the trial; control arm participants were seen by different clinical nurses. Additionally, the participants repeatedly referred to ‘you’ (addressing the researcher) as the one who had helped them.

A limitation of the study is that the concept of stigma emerged as an inductive theme during data analysis rather than being explored explicitly in the topic guides. Data on the experience of stigma and response to stigma was therefore not collected from all participants. However, despite this, stigma was a key feature of many patients’ experiences of trial participation, described by 25 of the 30 participants. Another limitation is that, due to the inclusion criteria for the wider trial, the findings represent the experiences of PLWH who have been on ART for more than a month and are experiencing non-acute moderate to severe pain or other symptoms. However, this does not negate the importance of the experiences of this patient group. Since interviews were conducted by the same researcher who implemented the study, some social desirability bias is possible. We chose to keep the same researcher for both study components because of her experience and skill in conducting palliative care research, as we believe this skill outweighed any potential bias. Finally, the qualitative interviews necessarily took place after the trial had finished and so could be affected by recall bias.

Our findings have direct implications for clinical care and research for HIV communities, highlighting the association between psychosocial care and increased resistance to HIV-associated stigma. Failing to tackle stigma is a significant threat to infection control, access to testing, adequate treatment, and healthcare utilisation. Stakeholders at all levels of HIV care provision should consider the potential effects

of increasing levels of compassion, communication and social support in the care they provide to help PLWH resist stigma. It may be possible to integrate this approach into other, more established roles that are included in recommendations for best practice, such as treatment navigators or peer educators (Simoni, Pantalone, Plummer, & Huang, 2007; Thompson et al., 2012).

Future research is needed to explore whether the hypothesised shame resistance mechanisms of connecting, refocusing, accepting, understanding and resisting do indeed contribute to stigma resistance in PLWHA. Stigma should also be measured using a standardised outcome measure such as the PLWH Stigma Index, adapted and validated in each cultural setting, to enable cross-study and cross-country comparison and service evaluation (dos Santos, Kruger, Mellors, Wolvaardt, & van der Ryst, 2014; International Planned Parenthood Federation, 2008).

The findings also have implications for researchers working with socially isolated or stigmatised groups, who should consider the beneficial effects of participating in research, which may be in addition to any overt therapeutic input, in study design. This has been discussed more fully elsewhere (Lowther et al., 2016).

Resistance to HIV-associated stigma is possible, and can be encouraged through compassionate communication and social support. If these findings can be replicated at a larger scale and in different contexts, this affordable and life-affirming approach could have considerable public health and clinical significance for management of the HIV pandemic.

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